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ABSTRACT

Improving prognosis for many forms of childhood cancer has resulted in increased attention on the quality-of-life experience. Conditioned anxiety and pain associated with recurrent diagnostic and treatment procedures have been identified as major sources of distress in children with malignant disease. To evaluate the efficacy of various psychological strategies for distress reduction, valid situation-specific measurement tools are required. A 25-item behavioral observation scale of distress during a selected procedure, bone marrow aspiration, was developed. Observations of 115 children with leukemia, ranging in age from 8 months to 17 years, 9 months, were collected. Trained observers were utilized, achieving an inter-rater reliability above .90. Results indicated clear age differences, with younger children exhibiting more distress behaviors and more gross motor behaviors than older children. Females exhibited more behaviors than males across age groups, also displaying more emotional interactivity than males. Behavioral observation and independent nurse ratings correlated .66. A replication and extention of the first study included a self-report measure of general affective state during the procedure. With a sample of 151 children, the self-report measure correlated significantly with objective behaviors and nurse ratings, but only for children above age six. Self-report scores, as with behavioral indicators, generally decreased with increasing age. (Author)

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DISTRESS BEHAVIOR IN CHILDREN WITH LEUKEMIA UNDERGOING MEDICAL PROCEDURES

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Multimodal medical treatment for many forms of pediatric cancer has resulted in an increasing number of children with these illnesses living for prolonged periods of time. Iatrogenic problems, both medical and psychological in nature, have been noted as results of prolonged and intensive cancer treatment (Kellerman, 1979; Katz, in press). As a psychologist with the Psychosocial Program, Division of Hematology-Oncology at Childrens Hospital of Los Angeles, one of my primary functions is to facilitate the adjustment of children with cancer to their illness and treatment. In the brief time allotted, I intend to present research findings collected over the last two years relating to behavioral distress in children with leukemia undergoing medical procedures, along with clinical and developmental considerations.

Conditioned anxiety associated with recurrent diagnostic and treatment procedures is a major source of distress in children with malignant disease (Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1979; Katz, in press). Such anxiety is often anticipatory (ocurring prior to the administration of medical procedures) and manifests itself in terms of a variety of symptoms: Nausea and vomiting, anorexia, insomnia, nightmares, withdrawal, and depression. Extreme agitation and uncooperativeness during procedures also

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characterize the responses of psychologically normal children subjected to recurrent medical stress (Kellerman, Katz, & Siegel, 1977). Though the medical procedures themselves - i.e., bone marrow aspirations, lumbar punctures, intravenous and intramuscular injections of chemotherapeutic agents - are the primary stimuli that evoke anxiety, substantial stimulus generalization occurs, so that children may exhibit anxiety in response to hospital locations, personnel, both temporal and sensory stimuli (sounds, sights, and smells), and other stimulus discriminants.

Although our clinical experience has demonstrated the utility of behavioral approaches in significantly reducing procedure-related distress, empirical research in this area has been hampered by the lack of relevant, situation-specific measurement tools. For this reason, we undertook the development of an objective, behavioral observation scale that would be useful in monitoring children's behavioral anxiety during medical procedures. Our study was limited to children with leukemia in order to control for illness-specific variables. The bone marrow aspiration (BMA) was selected for study because it is frequently repeated and reported as being highly stressful. Only BMA's administered in the outpatient Hematology-Oncology clinic at Childrens Hospital of Los Angeles were observed because of the standardized, controlled manner in which these procedures are performed (the same nurse administers all procedures, assisted by the same staff, in the same treatment room.).

Development of the observational scale began with the generation of a list of behaviors hypothesized to be indicative of anxiety during the procedure. Contributions to this list came from the literature, interviews with patients, parents, and medical staff, as well as our own extensive clinical observations. Twenty-five items were selected for the first scale, entitled the Procedure Behavioral Rating Scale (PBRS). Behaviors were operationalized, and the observation period was divided into four, discrete,

time phases. Trained observers stationed in the treatment room during the procedures noted the occurrence of behaviors in each phase, yielding four phase scores and a composite total score. Inter-rater reliability on this and subsequent studies was over .90.

Slide 1 displays the 25 behaviors initially included on the PBRS, along with selected operational definitions.

(Slide 1)

In our first study, observations were conducted on 115 individual children ranging in age from 8 months to 17 years 8 months. Eleven behaviors listed in slide 1 are followed by an "a", indicating behaviors that were subsequently removed from data analysis became of non-occurrence or low frequency (less than 2%). The behavior questions was removed because it correlated negatively with most other items, as well as with PBRS total scores. As such it appeared to be a counter-anxious response. In total, twelve behaviors were eliminated, with 13 remaining.

Major findings of this study are noted in slide 2.

(Slide 2)

As noted in slide 2, the presence of some behavioral anxiety in response to BMA's was virtually ubiquitous. The distribution was skewed to the left.

Independent ratings of the child's anxiety were carried out by the nurse performing the procedure after it was completed. Using a scale of 1-5, where 1=not at all anxious and 5=very anxious, the nurse circled the number that she perceived to best represent the patient's anxiety. Nurses appeared to be most sensitive to crying, screaming, and measures of cooperativeness (e.g., needs to be restrained), and less so to more "subtle" behaviors that were harder to observe (seeking emotional support). Nurse ratings correlated highest with Phase 3 scores, the phase in which the procedure actually took place. Nurses were apparently less sensitive to anticipatory behaviors (phase 1 and 2), or post-procedural behaviors (phase 4).

No stable pattern of habituation to the procedure was indicated. It should be noted that the range in time since diagnosis equaled 1 month to 6 years-4 months (mean= 2years-8 months)so all of the child had experienced at least two BMA's and as many as several dozen. Time since diagnosis, which is generally proportional to the number of procedures experienced, did not correlate with PBRS scores or nurse ratings. In addition, the time since the child's last procedure also did not correlate, suggesting this not to be a factor influencing anxiety. Finally, test-retest data on 27 children revealed no stable pattern of anxiety reduction. This finding will be further supported by data to be presented on a follow-up study.

Not only was there a main-effect for age on the number of behaviors exhibited, with younger children exhibiting quantitatively more anxiety, but a qualitative age difference was present as well. Younger children tended to exhibit a greater variety of behaviors over a longer period of time, with a developmental trend toward behavioral withdrawal and increased muscle tension with advancing age.

Females tended to exhibit more behaviors than males, across age groups, and to express more comfort-seeking as opposed to uncooperative behaviors. As noted, there were no age by sex interactions.

In our second study, a revised PBRS scale including 13 behaviors and a modified division of phases was used with 151 children ranging in age from 9 months to 19 years-9 months. In addition, a self-report measure was also included, in which the children were asked to rate their general affective state during the procedure immediately after it was completed.

(Slide 3)

The child was asked to select one of seven faces on a verbal-pictoral scale that ranged from feeling good (face 1), to feeling bad (face 7). This subjective measure was included because of the emphasis in the literature

on the subjective nature of anxiety and discomfort (Borkovec, Weerts, & Bernstein, 1977). This afforded us the opportunity to empirically investigate the relationship between objective and subjective measures of anxiety in this setting.

Major findings of Study II are presented in slide 4.

General replication of our first study indicated the stability of our measurement techniques. The self-report measure was consistent with our other behavioral measures in that younger children expressed more distress. However, correlations of the self-report measure with the PBRS and Nurse Ratings were significant only for the middle and oldest age groups. The insignificant negative correlations for the youngest children appeared to be due to restricted range on the self-report measure for these children. Over 85% of the children in this age range marked negative responses on the self-report (scores of 5,6, or 7), whereas there was a much wider range of scores for the older children.

Repeated observations on 58 children revealed no significant reduction over time on the PBRS, or self-report. This is viewed as further evidence for the non-habituation of children to this procedure. However, Nurse ratings did tend to go down over repeated observations for children in the 6-10 age range. This suggests that the nurse may not be as attentive to all the behavioral variables, or that they may be biased due to their personal knowledge and experiences with some children.

Bone marrow status, i.e., the rating of the bone marrow aspirate which represents the degree of leukemia involvement (remission or relapse), was collected for each child based on their BMA that immediately preceeded the one observed. This measure did not correlate with any of the other measures, suggesting that the level of illness did not significantly influence behavior during the procedure.

CURRENT RESEARCH DIRECTIONS:

We are presently engaged in a controlled study to investigate the effectiveness of clinical hypnosis in reducing anxiety and pain in leukemic children (age 6-10) undergoing outpatient BMA procedures. The PBRS and Nurse ratings will be used as dependent measures, along with two self-report measures. Rather than taking one general affective self-rating, we will now ask children to rate their level of experienced fear and pain. Fear will be rated on a scale similar to the previous self-report measure. Pain will be rated using a Pain Thermometer, as shown in slide 5.

(Slide 5)

Studies of clinical pain in children are exceedingly rare, as are studies evaluating the relationship of pain and anxiety. This study will also provide important data in this regard.

Another study we are beginning is an investigation of the relationship between beta-endorphin levels in cerebrospinal fluid of leukemic children (aged 6-10) and their behavioral response during spinal tap procedures. There is currently a great deal of interest in evaluating the potentially mediating effect of endogenous opioid compounds on the perception of pain and anxiety (Bendetti, 1979; Vereby, Volavka, & Clouet, 1978). In addition, we will also be collecting selected personality measures (particularly Trait Anxiety and Self-Concept) on the same children, to investigate their relationships with the other variables. One goal in this line of research is to develop predictive indicators of children at risk for severe reactions to procedures (and perhaps illness in general), so that effective early intervention can be instituted.

Pediatric cancer patients represent a psychiatrically normal population of children subjected to intense, repeated, stressful medical procedures. The study of their behaviors and coping styles in response to acute, controlled stressors such as medical procedures will facilitate

our understanding of acute anxiety and pain in children that may have implications to other chronically ill children, as well as to the non-ill population of children.

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SLIDE 1. PBRS ITEMS AND SELECTED OPERATIONAL DEFINITIONS

1. Cry: tears in eyes or running down face.
2. Cling:
3. Fear Verbal: says "I'm scared/afraid",etc.
4. Pain Verbal:
5. Scream:
6. Stall: Verbal or behavioral delay.
7. Carry:
8. Flail: Random gross movements of arms/legs.
9. Refuse Position:
10. Restrain: Has to be held down.
11. Muscular Rigidity:
12. Emotional Support: Verbal or non-verbal solicitation of comfort.
13. Request Termination:
14. Groan[a]: Non-verbal, vocal
15. Laugh[a]:
16. Stoic Silence[a]: Completely non-vocal.
17. Nausea Verbal[a]:
18. Vomit[a]:
19. Urinate/defecate[a]:
20. Kick[a]: With intention to strike.
21. Hit[a]:
22. Bite[a]:
23. Verbal Hostility[a].
24. Curse[a]:
25. Questions[b]: Non-delay, information-seeking verbal behavior.

Note: [a]=Items subsequently eliminated due to non-occurrence or low frequency.

[b]=Item subsequently eliminated due to inconsistency with remainder of scale.

Slide 2. Major Results of Study I (N=115, Age Range 8 months→17-8)

1. PBRS Total Score Range: 0-24

   Mean= 6.7, Median= 5.0, SD= 5.5

   Distribution of Scores

   0 = 3%
   1-5 = 50%
   6-10 = 25%
   11-15 = 12%
   16-24 = 10%

2. Independent nurse ratings of the child's anxiety correlated .66 with PBRS Total score.

3. No stable pattern of habituation to the procedure was indicated.

4. Significant Main Effects for age.

	AGE GROUP			
	I (8mos→6-4) n= 38	II (6-6→9-11) n= 38	III (10→17-9) n= 39	
PBRS MEAN Total Score	11.26 SD= 5.7	5.97 SD= 4.38	2.87 SD= 1.99	Oneway Anova Total by Age Group $F(2,112)= 37.43$ $P < .001$

5. Significant Main Effects for Sex

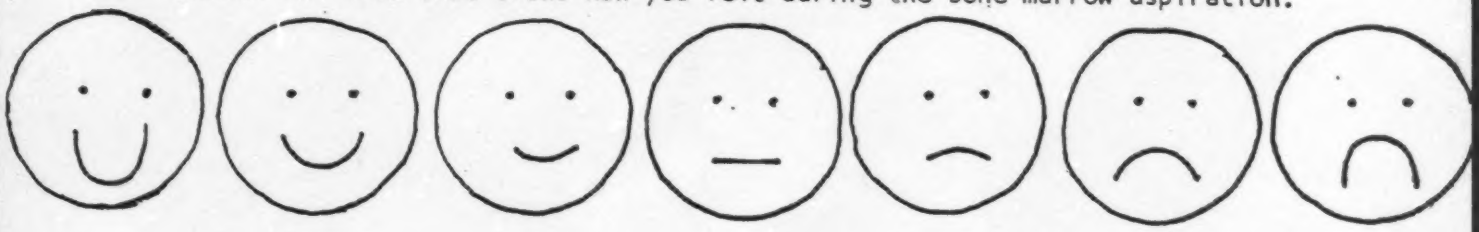
	Males (n=69)	Females (n=46)	
PBRS MEAN Total Score	5.93 SD= 4.99	7.78 SD= 6.08	Oneway Anova Total by Sex $F(1,109)= 5.13$ $P < .03$

6. No age by sex interactions.

Slide 3. PROCEDURAL SELF-REPORT FORM

Please take a look at these faces. Think of the face marked one as feeling real good, not bothered by anything at all. Think of the face marked seven as the biggest bother you can imagine, feeling real bad.

Choose the face that shows how you felt during the bone marrow aspiration.



1 2 3 4 5 6 7

Slide 4. Major Results of Study II (N= 151, Age Range= 9 months → 19-9)

1. Basic replication of Study I. Main effects for age and sex. High correlation with independent nurse rating (r= .71).

2. Self Report Scores

	AGE GROUP			
	I (3 → 6)* n=26	II (6-1 → 9-10) n=44	III (10 → 19-9) n=58	Oneway Anova Self-Report by Age Group
MEAN SCORES	5.73 SD= 1.61	5.41 SD= 1.77	4.38 SD= 1.64	F(2,125)= 7.71 P < .001

* Children below age 3 not administered the Self-Report measure.

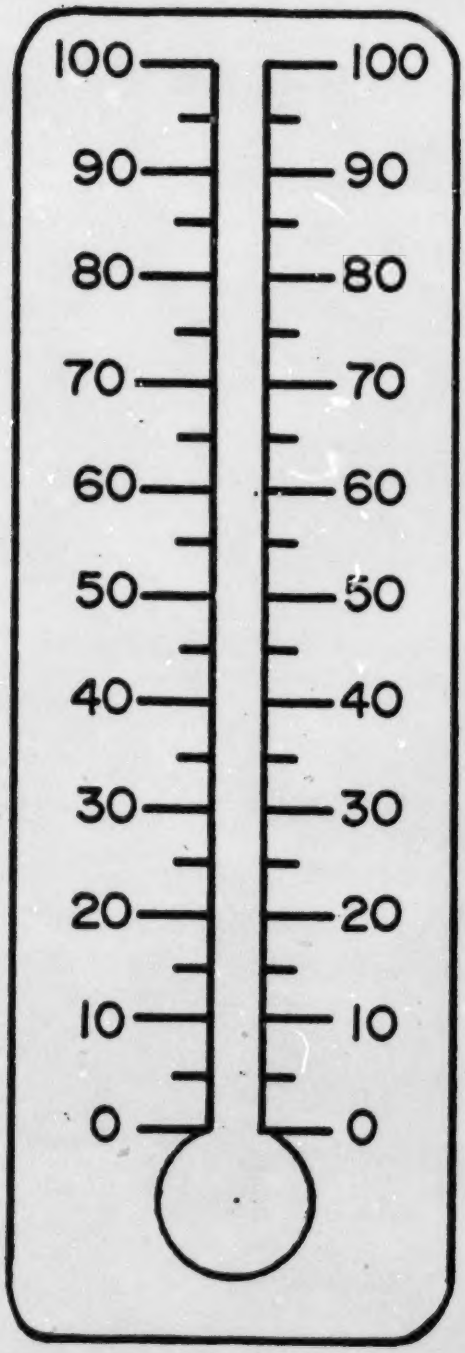
3. Pearson Correlations with Self-Report

	AGE GROUP		
	I	II	III
PBRS Total	-.17 NS	.36 P < .01	.54 P < .001
Nurse Rating	-.02 NS	.44 P < .01	.66 P < .001

4. No evidence of Habituation.

5. No relationship between Bone Marrow Status and PBRS, Nurse Rating, or Self Report.

Slide 5. PAIN THERMOMETER



This is a thermometer, just like the ones we use to tell how hot or cold something is. But this thermometer measures how much something hurts. At the bottom is zero - no hurt at all. At the top is 100, the most hurt you could feel. Use this red pen and fill in how much hurt you felt during the bone marrow aspiration.